A few facts about the Gibson Report

Margaret Williams 29th November 2006

The Gibson Report, whilst welcomed by many, has been publicly attacked by some ME/CFS patients and advocates as "atrocious" and "very poor indeed".

Reviews that have concentrated on the positive aspects of the Report have been criticised and the reviewers have been verbally abused, often forcefully.

Whilst there are indeed important issues over which the Gibson Report could have been expected to be more robustly informed, to attack the whole Report as has been done is likely to kill off any support which the ME/CFS community has been afforded by the Report.

The press coverage has been disappointing, which indicates either total disinterest in the whole subject or that the Science Media Centre is doing what it does very well (it has been confirmed by a broadsheet health editor that all information for publication on ME/CFS comes via the Science Media Centre – a body that was set up to provide "independent" scientific information to the media but whose views are largely in line with government policy and where Professor Simon Wessely is influential, being a member of the Scientific Advisory Panel), so for members of the ME/CFS community themselves to attack publicly the many strengths of the Report would seem to be a serious error of judgment.

It may not be generally known or appreciated that all Dr Gibson's assistants who worked so hard on the production of the Report gave their time entirely voluntarily and were unpaid: it was not uncommon to speak to them at 8pm when they were still working at the House of Commons – in their own time-- on the Report, and none of the researchers who worked on it had a medical or scientific background.

This is a far from ideal situation but is certainly better than no Report at all.

Some sections of the Report that have caused the most concern were in fact cut and pasted from the panel members' own comments that they felt strongly about and which they wished to be included.

The section on children was the issue that caused the most debate and conflict within the Group: it was the most contentious and it caused the most arguments. The published result on this issue was a compromise.

As Dr Gibson himself has pointed out, if he had not succeeded in obtaining a compromise and if the split in the Group members had not been overcome in the way it was, the result would have been really bad news for the ME community. Dr Gibson felt it was important

to retain Lord Turnberg as a member of the panel due to Lord Turnberg's recognised stature within the medical community.

It is a matter of record that one of the Group, Lord Turnberg (the former Professor Sir Leslie Turnberg, who was President of the Royal College of Physicians at the time of the production of the much criticised and biased 1996 Joint Royal College's Report on CFS) is a staunch supporter of Professor Simon Wessely about ME/CFS, as recorded in his eulogy in Hansard (House of Lords: 22nd January 2004: volume 656, number 27, column 1185: "*It so happens that Professor Wessely and his colleagues have led the field in (CBT). Rather than doing a disservice to patients, Wessely is doing them an enormous service and has devoted much of his life to caring for them. This is a man absolutely committed to caring for those patients").*

Indeed, it is understood that during the formulation of the Gibson Report, Lord Turnberg argued that there is no evidence that Wessely's views about the nature of ME/CFS are incorrect. Lord Turnberg was the one person in the Group who could have been expected to understand and take on board the vast amount of biomedical evidence that was submitted for consideration, but given his known views that support the psychosocial model of ME/CFS, that a consensus was able to be reached at all is surely a remarkable achievement.

Dr Gibson himself readily acknowledges that the Report does have shortcomings but he is convinced that it will serve as a valuable step towards obtaining for the CFS/ME community the recognition that is so urgently needed.

Areas of concern include not only the section on children and young people, but also on the known role of vaccination in the development of ME/CFS, but the Report recognises this and therefore calls for an independent inquiry by appropriately qualified and independent experts to consider the biomedical evidence. That must surely be the best way forwards.

There were without doubt tiresome errors in the released version: these included not only typos (the mis-spelling of Professor Chalder's name being one) but also the fact that the Index did not concur with the pagination (caused when the document was converted into a pdf version). However, technical corrections have now been made and a corrected version will be on the Gibson Inquiry website later today.

There are indeed apparent inconsistencies (one being the acknowledgement that CBT/GET is at best "*only a partial answer*", yet Professor Chalder's work in this field is described as "impressive"), but given the constraints under which the Group was forced to act and the firmly-held views of some of the Group members, this is hardly surprising.

Dr Gibson's office has confirmed that all feedback will be considered, and the Group will determine the best way forwards in the light of the feedback received.

Overall, the strengths far outweigh the undoubted weaknesses and the weaknesses (which are now likely to be addressed by experts as the Report recommends) should not be allowed to detract from the many strengths. It must not be overlooked that those strengths include the following:

- The MRC has been stringently criticised for psychiatric bias
- NICE has been stringently criticised likewise
- The correct WHO classification has been emphasised (ie. there is no "dual classification" of CFS/ME as claimed by Wessely School psychiatrists)
- The Oxford case definition has been criticised as including those who do not have CFS/ME
- The Report calls for immediate and substantial funding into the biomedical aspects of CFS/ME
- It castigates the DWP over its untenable stance about those with CFS/ME
- It exposes the misinformation about CFS/ME in medical textbooks
- It exposes – and calls for a full investigation by the appropriate standards body into – the blatant vested interests of those doctors advising the DWP who have consultancy posts with the medical insurance industry
- It calls for data on CFS/ME to be kept by the Department of Health
- It asks why, when not one single person who gave oral evidence asserted that CFS/ME is a primary psychosocial disorder, such a model has gained such prominence in the UK
- It calls for CFS/ME patients to be treated with care and compassion equal to that accorded to patients with heart disease or cancer
- It makes it very clear that CBT/GET are at best merely symptomatic treatments and it specifically warns against the potential dangers of GET for those with CFS/ME
- It highlights the fact that the UK is lagging behind other countries in biomedical research.

The one serious flaw is that although Dr Gibson and his researcher would very much like the Report to be available in hard copy, there are simply no resources available. However, independent ME/CFS researcher Mrs Doris Jones has agreed to produce a limited number of copies at cost price. She can be contacted by telephone on 0208-554-3832).

Dr Gibson's office has received many calls expressing gratitude for his Report, and such gratitude is well-deserved.

The Gibson Report is the best Report on CFS/ME to appear since the National Task Force Report in 1994; it should be acknowledged as such and its many strengths should be recognised and utilised.